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POLICY NOTE

Challenges to Sustaining California's Developmental Disability Services System

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SUMMARY: California's developmental disability services system is currently facing severe budget reductions as part of Governor Brown's efforts to close the state's budget gap. For more than a decade, guaranteeing adequate funding for these services has been challenged both by a dramatic increase in the number of individuals eligible for these services and by limited resources, rate freezes, and inadequate transparency in resource allocation. These factors threaten the financial solvency of service providers, potentially resulting in decreased access to high-quality care and increasing the cost of care for the state. As the only state in the nation that has established an entitlement for developmental disability services, California must pursue multiple strategies in order to meet the goals of this entitlement and to ensure both adequate and equitable access to high-quality and cost-effective services. This policy note discusses the background of California's developmental disability services and identifies the challenges facing this system. It recommends that the state adjust frozen rates for services, adopt equitable and transparent vendor payment systems, and maximize the efficiency of the current system of service provision, among other policy solutions.

Background

The statutory framework for provision of services to individuals with developmental disabilities in California was established in 1969 by the *Lanterman Developmental Disabilities Services Act* and its later amendments ("The Lanterman Act," Welf. & Inst. Code §4500, et seq.). This bill defines a basic right of individuals with developmental disabilities to receive, and a corresponding obligation of the state to provide, regional community-based services that "maximize opportunities and choices in living, working, learning, and recreating in the community" (Welf. & Inst. Code §4640.7).[1] Services for individuals with developmental disabilities are an entitlement in California and are intended to minimize institutionalization and enable independent living within the least restrictive environment possible (Welf. & Inst. Code §4502).

Services can be generally categorized into three core types: residential care, community programs, and transportation services.[2] Community programs provide a variety of services, including day programs (e.g., social skills training, behavioral intervention, and therapeutic treatments), in-home respite (relief for family caregivers), supported living, supported employment, and work activity programs.[3, 4] Residential settings primarily include Intermediate Care Facilities (ICFs) and Community Care Facilities (CCFs), both providing care at various levels of need, as well as State Developmental Centers (SDCs), which are residential facilities providing habilitation and treatment.[5] The majority of consumers live and receive services in the community. In 2007, those receiving services resided in one of the following settings: with a family member or guardian (73%), a CCF (12%), an independent or supported living program (9%), a skilled nursing facility or ICF (4%), an SDC (1%), or another type of setting (1%).[6, 7]

Responsibility for implementation of the services authorized in the Lanterman Act is divided between the Department of Developmental Services (DDS) and twenty-one private, nonprofit Regional Centers (RCs).[1] The DDS system, which was allocated about $4.5 billion in the 2010–2011 state budget, currently serves more than 244,000 consumers. That number is expected to grow to nearly 252,000 consumers in the 2011–2012 fiscal year.[1, 8-10] In budget year 2009–2010, 52 percent of the RCs funding came directly through the state's

general funds, with the remaining resources funded through a mixture of federal and state sources, as well other sources such as parental fees.[6, 11] The DDS acts as the budget intermediary with an oversight capacity, while the RCs are delegated the day-to-day responsibilities of determining diagnosis and eligibility, as well as carrying out the state's obligation to provide care to eligible individuals.[2, 12] The California Welfare and Institutions Code defines "developmental disability" as a disability that originated before the individual was eighteen years of age, continues or can be expected to continue indefinitely, and constitutes a substantial disability for the individual. To be eligible to receive DDS services, an individual must have been diagnosed by an RC or, if under three years old, must exhibit substantial developmental delay.[6]

Once eligibility is established, the RC conducts an individual planning process and develops an Individual Program Plan (IPP) or, for a consumer younger than three, an Individualized Family Service Plan (IFSP). This process involves setting specific goals and determining which services will best meet the individualized needs and preferences of the consumer. The RC then engages in service coordination to ensure that services in the IPP or IFSP are obtained. This can be either through generic agencies (publicly funded agencies that have a legal responsibility to serve all members of the general public – for example, Medi-Cal, County Department of Health, and In-Home Supportive Services), natural supports (family members or friends), or if no generic agency is available, through purchase of services from vendors using RC funding.[1, 6]

Among those consumers served in the community in 2007, about 78 percent received RC-funded services.[7] Services are provided to the consumer free of charge, with these exceptions: an income-based family cost participation requirement for individuals ages three to seventeen who are living at home and receiving respite, day care, or camp services; and family cost sharing for 24-hour out-of-home placement of children.[6]

The RC process of selecting vendors, referred to as "vendorization," consists of identification, selection, and utilization of service providers.[13] The Lanterman Act and Title 17 of the California Code of Regulations (Title 17, CCR) require that the vendorization process consider the following: (1) a provider's ability and past success in delivering quality services; (2) the existence of appropriate licensing, accreditation, and certifications; (3) the cost of providing services of comparable quality; and (4) the consumer's choice of provider.[2] Often, multiple vendors operate under a single business entity, as one entity receives multiple unique vendor numbers for each service type provided within each RC.[14] Of the 45,000 vendors who provide services, 40 percent are private nonprofits and for-profit agencies, and 60 percent are parents or other family members of DDS consumers.[6] Nonprofits are prevalent in the vendor community: among the 100 business entities with the highest level of total RC expenditures during fiscal year 2008, 51 percent were nonprofits, accounting for more than 1,130 vendors and over $466 million in purchased services.[14, 15] Vendors of supported employment programs are required by statute to have nonprofit status (Title 17, CCR §54351).

Challenges

The developmental disability service system faces two distinct types of challenges: (1) the increasing need for and cost of services, and (2) limited resources, rate freezes, and insufficient transparency in resource allocation.

Growing Needs and Costs

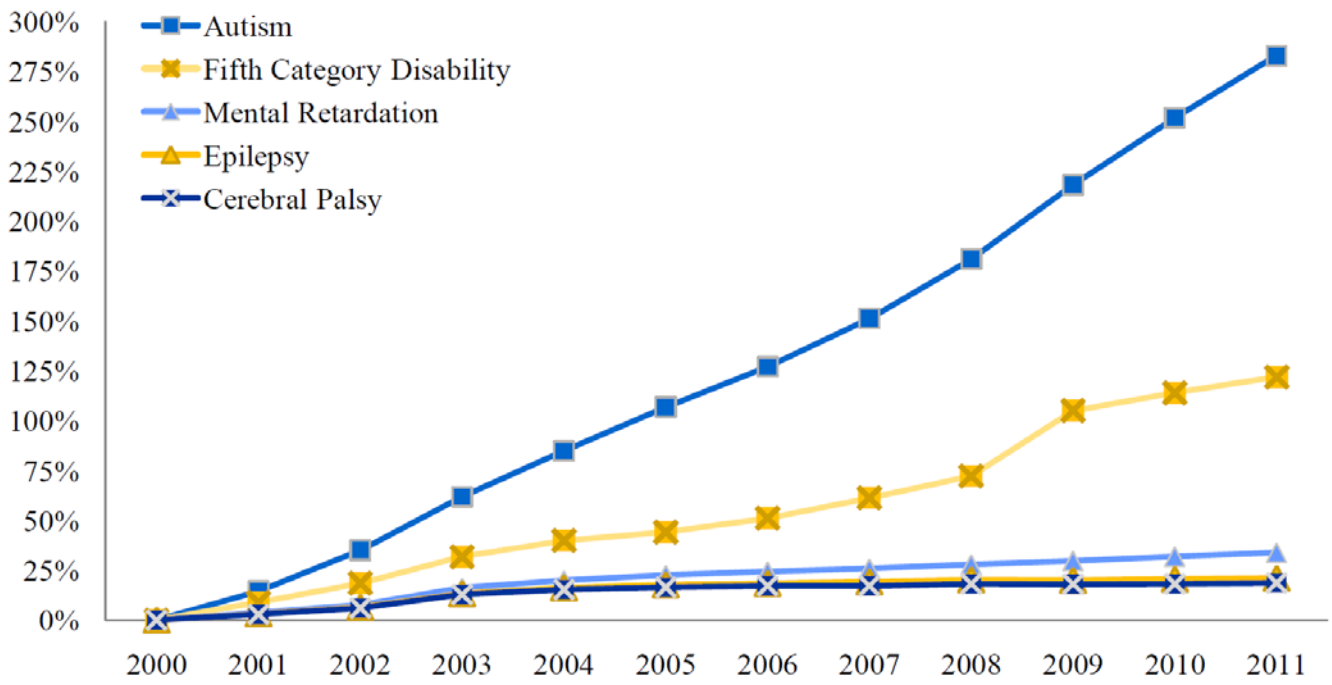
Growth in DDS Population Served in the Community

The overall number of DDS consumers has increased by 57 percent since 2000, while the general population of California has grown by only 14 percent during this same period.[8, 16] Specifically, the population of children under the age of three receiving early start services in the community has increased by 62 percent, and the population of DDS consumers over age three who are served in the community has increased by 53 percent.[8, 17, 18] The addition of new consumers accounts for 43 percent of the growth. However, the growth in the population served in the community, and the associated costs of such care were also impacted partially by the implementation of a planned closure of SDCs. The population of DDS consumers served in these facilities has decreased by 48 percent since 2000.[8] In 2007, the average per capita cost of care in SDCs was almost $276,000, compared to $16,165 in the community.[6] Moving SDC residents to community care settings accounted for 24 percent of RC expenditure growth between 2000 and 2007.[6]

Booming Autism Rates

Ongoing increases in the prevalence of individuals diagnosed with Autism Spectrum Disorders (ASD) have led the Centers for Disease Control and

Exhibit 1. Growth in California population with autism versus three other major developmental disabilities and the "fifth category," 2000–2010



Notes: Developmental disability groups are not mutually exclusive, due to potential duplication of individuals across diagnostic categories. The "fifth category" refers to disability conditions found to be closely related to mental retardation or to require similar treatment (Welf. & Inst. Code §4512).

Source: Authors' analysis of data provided by Department of Developmental Services Data Extraction Unit; 2011.

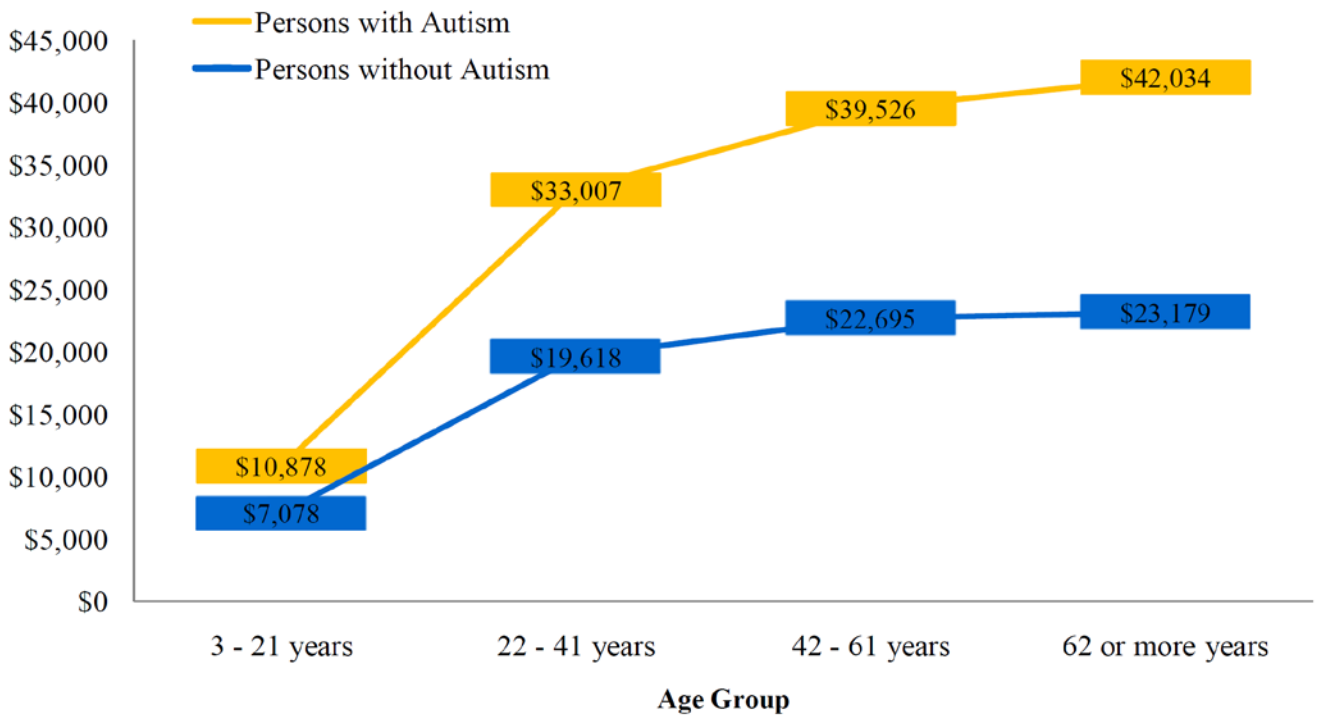
Prevention (CDC) to declare ASD an urgent public health concern.[19] In California, the number of people with autism served by DDS has grown by 283 percent since 2000.[8] However, the annual growth rate has been steadily declining since 2003, indicating a potentially lower expected growth in the next decade. Since 2003, the incidence of other major developmental disabilities has also increased, among them: mental retardation (34%), epilepsy (21%), cerebral palsy (19%), and the "fifth category," representing conditions resembling mental retardation or requiring similar treatment (122%).[8] Additionally, the proportion of DDS consumers with higher needs due to dual diagnoses (mental illness and developmental disability) increased by 48 percent between 2001 and 2006.[6, 20]

Expenditures for individuals with autism are higher than those for individuals with any other type of developmental disability in every age group. In the provision of services to consumers with autism, the cost of serving children is lower than that of serving adults. The reason for this differential is that children are likely to live at home and use educational services paid for by school districts rather than by DDS, whereas adults have an increased need for community services or residential care.[7, 21] Specifically, in fiscal year 2006–2007, the average per capita cost of serving individuals with autism ages twenty-two to forty-one was 203 percent higher than the per capita cost for individuals with autism ages three to twenty-one (Exhibit 2).[7]

Aging of the Current DDS Population with Autism

The age composition of the DDS population diagnosed with autism is expected to shift in the coming years, affecting the cost of services. In 2007, 83 percent of the DDS population with autism was concentrated at ages three to twenty-one; 13 percent were ages twenty-two to forty-one; 4 percent were ages forty-two to sixty-one; and 0.2 percent were age sixty-two and older.[7] As the large proportion of individuals ages three to twenty-one transition to adulthood, DDS will face a substantial cost burden.[21] Because information is not readily available on the severity of the condition for each individual consumer, it is difficult to predict with precision the increased cost of DDS services as consumers age.

Exhibit 2. Average annual expenditure per consumer by age group for those with autism and those without, Fiscal Year 2006-2007



Source: Department of Developmental Services, *Factbook, 11th Edition*, 2008, State of California, Department of Developmental Services.

Prolonged Life Expectancy of the Eligible Population and Aging of Informal Caregivers

Medical advances across the lifespan and improved health care have resulted in increased life expectancies among individuals with developmental disabilities. As a result, consumers require services for longer periods of time, as well as services at a higher intensity during their later years of life. Additionally, the aging of the eligible population is accompanied by the aging of their caregiving parents, leading to an increased level of need for supportive formal services. When a caregiver dies, a DDS consumer likely requires an alternative residential setting at a high cost.[6]

Limited Resources, Rate Freezes, and Insufficient Transparency in Resource Allocation

Recent Budgetary Cuts

The current state fiscal crisis further exacerbates DDS's increasing budgetary pressure, given the growing demands for care and the rising costs of that care. Although it has not yet been enacted, Governor Brown's budget currently proposes substantial reductions to the DDS system.[9, 22] As this policy note goes to press, budget discussions indicate a potential reduction of more than $500 million in the total budget available for developmental services, including a $174 million cut to be achieved through potential implementation of statewide purchase of service standards, among other cuts.[23] Additionally, it is proposed that current rate freezes be extended and vendor payment reduced by 4.5 percent through June 30, 2012.[10] Moreover, a 10 percent Medi-Cal rate cut is proposed, which will impact payments to vendors reimbursed via the Medi-Cal fee schedule.[24] Finally, the loss of federal matching funds will further reduce overall available funds.

Complex and Fragmented Rate Setting

The reimbursement rates for services provided by vendors are determined through differing rate-setting methodologies for different types of services, as stipulated in Title 17 CCR. Reimbursement rates may be based on a statute-defined rate, or they may be reached via a variety of cost-based methodologies, "usual and customary" rates, and rates negotiated between vendor and RC. [25, 26] The "usual and

customary rate" provision requires that rates reflect what is "regularly charged" by the vendor for the specified service to non-RC clients (Title 17, CCR §57210). In those cases where none of the above rate-setting processes is applicable, the vendor receives a negotiated rate from the vendoring regional center (Title 17, CCR §57300).

Insufficient Transparency and Accountability and Potential Non-Equitable Negotiated Rates

An amendment to the Lanterman Act passed in July 2009 established a requirement that RCs select the least costly available provider of a comparable service; the requirement to use cost-effective services is repeated in several parts of the act. However, the concepts of "cost-effectiveness" and "comparable services" are not defined in the statute, making it difficult to establish clear guidelines for vendor selection.[2, 6]

Additionally, RCs are charged with the authority and discretion to establish vendor payment rates for 96 of 155 active service codes, which account for almost half of total purchased services.[5] Should negotiations be required, the law and regulations do not mandate their format, content, or quality, nor do they require the RCs to document the negotiation process.[2] The California State Auditor has noted alarming examples of poor or nonexistent documentation of the RC rate-setting process, as well as cases of allegedly unethical rate-setting practices, failure to comply with Title 17 CCR regulations, and apparent disregard for the established rate freeze.[2] Lack of documentation may result in negotiated rates that may not be cost-effective and equitable.

Ongoing Rate Freezes

Since 2003, rates for many services have been frozen or restricted by the state, and on July 1, 2008, negotiated rates with all preexisting vendors were frozen.[6] Rates for new vendors established after that date are required to be less than or equal to the lower of either the statewide or regional average rate for the service type in question; once they have been set, these rates are also subject to the freeze.[2] Finally, existing law require that RCs reduce by 3% all vendor payments for services delivered between February 1, 2009, and June 30, 2010, and by 4.25% all vendor payments for services delivered between July 1, 2010, and June 30, 2011.[10] True operating costs of vendors are unknown, and current rates for some providers may not correspond with operating costs.

Can California Continue to Provide High-Quality and Cost-Effective Developmental Disability Services?

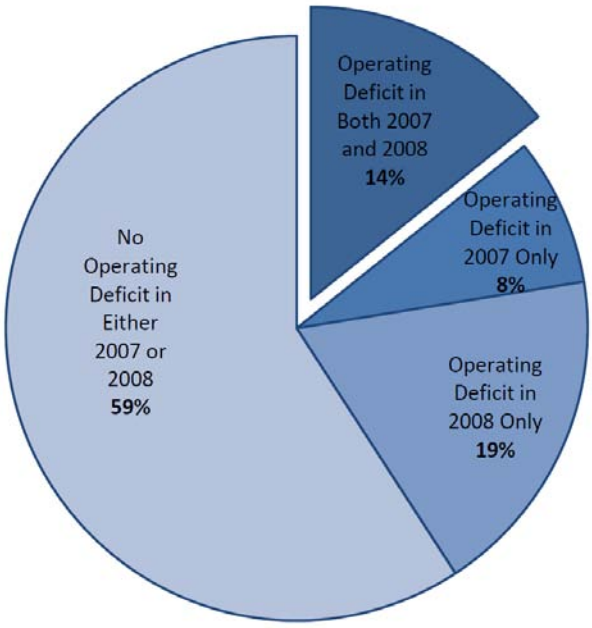
Potential Loss of Equitable Access to High-Quality Care

The continued financial health and operational capacity of RCs and their vendor network are necessary to the state's ability to provide high-quality services to individuals with developmental disabilities. Widespread rate freezes and payment reductions may ultimately harm vendors' financial viability. It has been shown that in response to increasing costs without corresponding rate increases, vendors offer lower pay to staff than do comparable employers. Given this competitive disadvantage, vendors struggle to recruit and retain direct-care staff, and newly hired staff often have less experience and lower levels of education than those whom they are replacing.[27]

Turnover among service providers is not predicted by low wages alone, but rather by a complex set of factors, including benefits such as paid time off and vacations.[28] The shortage of qualified direct-care personnel may impact the ability of providers to adequately meet the needs of service recipients.[27] The current frozen rate levels require vendors to absorb increasing implicit and explicit costs, thereby threatening vendors' financial solvency. Specifically, the rate freezes instituted in 2002 have neglected the 22 percent increase in implicit costs due strictly to inflation.[29]

Financial challenges that restrict the ability of nonprofits to operate as DDS service providers are of special concern, given their prevalence in the vendor community and their mandated involvement in providing supported employment. In some settings, such as nursing homes, nonprofit organizations have been shown to provide better quality care than for-profit facilities.[30, 31] To be consistent with their underlying mission to provide services to those in need, nonprofits are likely to offer services to any consumer, regardless of profitability. In contrast, for-profits are potentially able to risk-select consumers with lower perceived levels of need, or to minimize expenditures to maximize revenues.[31, 32] Among the 51 large nonprofits within the top 100 business entities in the DDS system in 2008, 16 (about 30%) reported an operating deficit, substantiating concern about their financial viability.[15] Such threats to the supply of services may fundamentally restrict consumer access and counteract the entitlement function of the Act.

Exhibit 3. Operating Deficits among the 51 Highest Expending Nonprofits in the DDS System, 2007 and 2008



Source: Authors' analysis of IRS Form 990 tax filings for 51 nonprofits within the 100 highest expending business entities in the DDS system in FY08, based on data generated by Department of Developmental Services Data Extraction Unit; January 2009.

Cost of Vendor Financial Insolvency to the State

Threatened financial insolvency of vendors, given rate freezes and inadequate reimbursement levels, may result in higher costs of care for the state. For example, Governor Brown's budget proposes a 10 percent rate cut for all Medi-Cal providers, including ICFs, beginning in June 2011. This rate cut would come on top of the 2009 freeze on reimbursement rates for these facilities.[24, 33] Almost 9,000 DDS consumers lived in skilled nursing facilities or ICFs in 2007.[7]

Some predictions suggest that as many as 5 percent of ICF beds will be lost as a result of rate cuts, requiring transfer of these consumers to other care facilities.[34] Should these consumers need to be transferred to SDCs, which are more costly to the state, a portion of the savings achieved by reducing the SDC population over the last decade may be lost. The annual per capita cost of care is about $70,000 for individuals residing in ICFs, compared to almost $276,000 for those in SDCs.[6, 34] Although half of the cost of care in both settings is offset by federal reimbursement, the increased cost to the state would be significant.

Policy Recommendations

Based on our analysis of the challenges facing the California developmental disability services system, we propose the following policy recommendations to ensure both adequate and equitable access to high-quality, cost-effective services throughout California.

Adjust Frozen Rates to Ensure Vendors' Financial Viability and Continued Access to Care

Establishing a fee schedule that is informed by thorough cost-based analysis and that incorporates adjustments for the increasing cost of service provision would allow vendors to sustainably maintain operations by limiting undue fiscal strain. A cost-based analysis recognizes the inherent variability in consumer needs -- where more severe conditions require more intense and expensive services -- and it also engages stakeholders in the rate-setting process.

Furthermore, the cost statements required for rate-setting should reflect the true costs of providing efficient and high-quality services, as required by the California Welfare and Institutions Code §4690. This would allow for the consideration of any mechanisms that have been employed by vendors to reduce costs in a rate-restricted environment in order to maintain solvency. The inclusion of an explicit adjustment for input price inflation, such as the Consumer Price Index (CPI), would mitigate threats to access by recognizing the ongoing cost increases faced by vendors.

Adopt Equitable and Transparent Vendor Payment Systems

Promote Transparency and Accountability

The California State Auditor's report of 2010 recommended establishing a uniform and transparent rate-setting process to improve cost effectiveness; that recommendation resulted in initial efforts by the DDS to implement reforms. However, the scope of the reforms focuses on a directive requiring RCs to "document how they determine that the rates they negotiate or otherwise establish are reasonable for the services to be provided."[2] Additional efforts to increase transparency in vendor selection and vendor payment are needed, and oversight of the process at every level should be increased.[2] For negotiated rates to properly demonstrate cost-effectiveness, standard definitions of the terms "cost-effective" and "comparable services" should be developed.[7] A clear, uniform definition of

these terms will facilitate clear guidelines of vendor selection.[2, 6]

Extend Comprehensive Vendor Cost Reporting Requirements to All Service Types

Standardized, comprehensive reporting of finances and utilization by both vendors and RCs will lay the groundwork for a more efficient, cost-effective, and transparent system. One of the major obstacles to reconciling the cost of services with shrinking budgets is the lack of detailed data on current costs for service types that at present do not require cost reporting. Enhanced reporting can support appropriate cost-based reimbursements, such as those implemented by the Federally Qualified Health Center (FQHC) program.[20] A comprehensive cost-reporting mechanism to inform RC budget processes and rate-setting negotiations can facilitate transparent evaluations of vendor and service sustainability, as well as reduce variability and inequity in vendor payments. In the setting of a severe budget deficit statewide, cost documentation would be valuable in informing difficult state budgetary decisions.

Implement a Standard Negotiated Rate System

A standard rate system for services that currently do not have a particular rate-setting method, such as transportation and behavioral services, would promote equity between vendors and service codes, limit wasteful spending, and protect vendors with less financial resiliency, including nonprofits and the parents of consumers.

Maximize System Efficiency

Develop Efficient Service Provision

Conducting real-time reviews of opportunities to minimize the marginal costs of additional DDS consumers and to eliminate inefficient service selection, without compromising the quality of care, could assuage the reduction in overall funding. For instance, if group-setting care can be demonstrated to be as effective as individual-setting care, RC strategies should maximize group service provision.[6] Additionally, establishing a more competitive bidding process for vendor selection or a "preferred provider" system might enhance efficiency.[6]

Governor Brown's proposed trailer bill language for the 2011–2012 budget discusses the establishment of statewide purchase-of-services standards in lieu of the independent standards currently decided at the RC level.[22] The development of such standards should be done in the context of a careful examination of successful mechanisms that promote the delivery of high-quality equitable services rather than in the context of budget reduction efforts. Such standards should not be utilized to impose artificial caps on reimbursement rates, to eliminate service, or to limit the flexibility or the availability of appropriate services and supports as determined in the IPP.

Identify and Use Additional Funding Sources

Sources of additional funding outside of the DDS budget should be maximized. Existing regulations require RCs to use generic services before purchasing services, but a clear methodology ensuring compliance is lacking.[6] Additionally, federal Medicaid reimbursement should be maximized in a number of DDS service areas, including the Home and Community–Based Services (HCBS) Waiver.[35] The state has undertaken some efforts to enhance federal reimbursement, such as increasing the enrollment cap under the HCBS waiver in 2008.[9] However, in 2007, as many as 1,100 consumers were being served in facilities that were not eligible for waiver participation, representing a lost opportunity for federal reimbursement of as much as $10.7 million.[6, 35] Further benefit can be gained by ensuring service coordination with private insurance plans to prevent duplication of benefits.[36] Finally, it has been suggested that the family cost-participation plan, currently in place for a small number of services, should be expanded to include additional services.[6, 9] However given the very high cost of the vital services required by many of the individuals served by DDS, it is essential that income levels or other qualifying criteria be carefully evaluated to prevent catastrophic financial consequences for families.

Conclusion

California's DDS system faces considerable challenges due to rate freezes that have extended for more than a decade, despite ongoing growth in both the demand for services and in the underlying costs of providing services. The policy recommendations presented above suggest that the legislature and governor need to give serious consideration to finding additional solutions to these challenges.

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25. Cost elements include basic living needs, indirect costs, direct supervision, special services, and a proprietary fee (which covers fixed assets). (Title 17 CCR §56910)
26. For supported employment services, standard rates are established by law (Title 17 CCR §58881). Rates for services similar to those covered by the Medi-Cal program are established by the Department of Health Care Services (DHCS) and cannot be lower than Medi-Cal's established rates. For community-based day care programs, independent living services, and work activity programs, DDS uses a rate-setting procedure based on staff-consumer ratios and vendor cost statements. DDS uses an alternative rate-setting methodology that considers vendor cost statements, income, and the permanent rates established for comparable vendors to set the rates for in-home respite care agency vendors (Title 17 CCR §58100). Rates for CCFs are established through the Alternative Residential Model (ARM) rate-setting methodology, based on median costs per consumer per month and varying by levels of care and geographic location (Title 17 CCR §56910). Other residential services provided by ICFs are funded by Medi-Cal through the Department of Health Care Services and are eligible for 50 percent reimbursement from federal funds for those ICF residents who are Medi-Cal eligible. Supported living services and Family Home Agency services are required to be negotiated on a contract-by-contract basis with the RCs (Title 17 CCR §58660-§58663, §56082). Transportation service rates are either set through “usual and customary” methodology or are negotiated (Title 17 CCR §58540).
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